

# The effect of dementia on patients, informal carers and nurses

Aileen Murray explores the implications for three groups affected by the condition and how greater awareness of these results in improved experiences for individuals

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## Abstract

This article explores the effect of dementia on individuals with dementia, their families and nursing staff. It explores the diagnostic issues that are important for individuals, the effect of symptoms and avenues of support. The need to adapt to different roles and the importance of communication are discussed for families and informal carers. Lastly, the culture of nursing care and the need for education, training, professional development and clinical supervision is discussed.

The literature emphasises the need for close collaborative working between those involved in dementia care, with individuals with dementia at the centre of decision making. It highlights how everyone involved can contribute to positive care experiences for those with the condition.

## Keywords

Care provider, cognitive impairment, collaboration, dementia, family, mental health

IN 1906, German neuropathologist and psychiatrist Alois Alzheimer gave a lecture in which he described the case of Auguste Deter, a 51-year-old woman whose symptoms included memory loss, disorientation and hallucinations. Ms Deter died at the age of 55. At post-mortem cerebral atrophy was noted and neurofibrillary tangles and neuritic plaques were identified in her brain. The condition was later known as Alzheimer's disease, which is the most common cause of dementia (Alzheimer's Disease International (ADI) 2014).

Dementia is defined as (World Health Organization (WHO) 2010): 'A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning

capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.'

## Incidence and prevalence

Worldwide, an estimated 36 million people live with dementia. This figure is expected to almost double every 20 years, to 66 million by 2030 and 115 million by 2050 (WHO 2012). Prevalence for men and women doubles for every five-year age band after the age of 65 (ADI 2008).

The Alzheimer's Society (2013) estimates that there are approximately 800,000 people in the UK who are living with some type of dementia. Prevalence rates by age are shown in Box 1.

Depending on the type of dementia diagnosed, symptoms may vary. Of the 100 or more illnesses and conditions that may cause dementia, most are rare. Of people with dementia, 62% have Alzheimer's disease and 17% have vascular dementia, while 10% have both (Alzheimer's Society 2013). Other dementias include dementia with Lewy bodies, Parkinson's dementia and fronto-temporal dementia.

## Diagnosis

National Institute for Health and Care Excellence and Social Care Institute for Excellence (NICE/SCIE) (2006) guidance states that a diagnosis of dementia should be confirmed through a range

### Box 1 Prevalence rates of dementia by age in the UK

- 40-64 years: one in 1,400.
- 65-69 years: one in 100.
- 70-79 years: one in 25.
- 80+ years: one in six.

(Alzheimer's Society 2013)

of procedures including cognitive tests such as Mini Mental State Examination and scans such as computed tomography (CT), magnetic resonance imaging, single-photon emission CT and molecular neuroimaging with positron emission tomography. These tests can rule out treatable conditions such as depression or vitamin B<sub>12</sub> deficiencies, which can present with similar symptoms.

In their review of early onset – under the age of 65 years – illness, Svanberg *et al* (2011) identified that individuals, regardless of age, experience difficulties in diagnosis or long delays in receiving a confirmed diagnosis, which result in discrepancies in diagnosis rates (Alzheimer's Society 2013). Identified barriers to early diagnosis include poor awareness, lack of training in primary care and lack of specialist diagnostic centres or memory clinics.

Objective two of the National Dementia Strategy (Department of Health (DH) 2009a) is good quality early diagnosis and intervention for all, which involves 'rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis'. In addition, early diagnosis ensures people can plan for the future. Living with dementia as the disease progresses presents a significant challenge, as does living with the stigma associated with the illness. Non-disclosure is common, with the individual trying to conceal symptoms due to embarrassment. However, disclosure may feel like 'owning up' (Roach *et al* 2008) and sharing the diagnosis may be part of the coping process.

One interviewee told Harris and Durkin (2002): 'I tell everybody, you have no choice on this. You are in control of something [telling people] even if it is only that. What someone with this diagnosis can do is let people know.' This vignette shows that there can be hope, humour and growth (Aminzadeh *et al* 2007) after diagnosis. Initially, a diagnosis of dementia may be received with 'severe shock, with feelings of disbelief, anger, loss and grief' (SCIE 2013), but it can also provide a sense of relief after a difficult period of uncertainty.

## Effect of dementia

**Individuals** In recent years, the subjective experience of dementia has been the focus of research reflecting a more person-centred approach, as families, friends and carers try to understand the experience of the person with the condition. Kitwood's (1997) work symbolised a significant shift in dementia care, challenging traditional perspectives while outlining the

complexities of the illness. His work highlighted the need to ensure individuals were placed at the centre of their care, affirming their personhood and self-identity at all times.

Roach *et al* (2008) explored the experiences of younger people with the condition and identified three core themes: diagnosis, relating and restructuring. 'Relating' had a predominantly negative focus, inducing feelings such as guilt, helplessness and uncertainties related to the disease. Loss and grief were often experienced, with emphasis on 'loss of role, purpose, meaning, relationships, activities and identity'.

Coping with the illness, or 'restructuring', was a more positive adaptation phase. Harris and Durkin (2002) refer to 'role relinquishment and replacement', whereby roles are changed as a result of dementia and replaced with new positions and responsibilities. However, the distress that role change causes cannot be overlooked, such as the individual developing feelings of dependency or being treated like a child.

A sense of loss of control as symptoms become more pronounced has a major effect on individuals. Robinson *et al* (2012) identified a discrepancy between individuals' perceptions of their illness and symptoms and those of others. As a result, people with dementia may experience a loss of self-esteem and a changing sense of self. In addition, the traditional and prevailing perspective of dementia maintains that the illness is a threat to self-identity, characterised by multiple losses arising from cognitive decline, worsening orientation, reasoning and communication abilities. The result is a stream of distressing experiences for the 'sufferer' when misunderstanding or being misunderstood. These negative experiences are emphasised by narratives such as Sterin's (2002), who felt as if she was 'becoming invisible' as her condition worsened.

When describing her mother's illness, Grant (1998) stated 'the disease begins to turn its malign attention to the very heart of her self, as she struggles to hold her identity together', and Matthews (2006) further reflects this view, quoting carer experiences when trying to make sense of and cope with dementia and its associated symptoms: 'He's not the man I married' or 'She's not the mum I used to know'.

Roach *et al* (2008) and Nowell *et al* (2013) state that individuals with dementia need to reconstruct their self-identity to cope with and accept the experience. The ability to cope successfully requires an 'affirmation of past sense of self and identity' and there is a need for positivity and self-acceptance in the adaptation process. Individuals need to register, react

and adapt to the changes induced through dementia. If none of these occur successfully, interrelated coping mechanisms are not 'activated' (Clare 2003) and there is a threat to self-identity. As the illness progresses, the symptoms that are experienced may detract from the individual's identity.

This is a significant challenge because of the disease's poor prognosis, and living with the knowledge of the predicted deterioration in mental and physical health can be difficult to accept. Acknowledging that memory will decline and wanting to maintain a sense of self and identity (Harman and Clare 2006) make demands on individuals' abilities regarding self-preservation, and there will be an emotional response to this adaptation phase.

It is important to develop strategies to cope with perceived changes in loss of control, self-esteem and self-identity, for example, normalisation of everyday routines and structures. These strategies help individuals to gain control over the illness, and maintain independence, meaning and motivation. Adjusting to the illness and its challenges requires people to draw on what they know about themselves.

In a study examining the effect of being diagnosed with early Alzheimer's disease on identity construction, Beard (2004) highlighted three themes: defining moments, to tell or not to tell, and preservation. To preserve the identities they had before the disease, respondents used strategies to minimise 'exposure' of their difficulties, for example, they would avoid social events or tasks such as driving or cooking. Similarly, they evaded awkward questions or conversations to prevent difficult situations.

Beard *et al* (2009) explored how those with dementia cope by managing the condition as a disability, and incorporating this mindset into their existing identities. Respondents reported that using aids such as cognitive reminders, modifying their environments, assistance from others and acceptance of their symptoms by others, were important. Beard *et al* (2009) claimed that by reframing dementia into a disability, those with the illness felt more empowered about maintaining their identity.

**Informal carers** Those who look after family members, partners or friends who are in need of help because they are ill, frail or have a disability can be called informal carers.

Carers of those with dementia face multiple challenges and numerous losses. It is well established that caring for a relative with dementia can lead to financial difficulties, social isolation,

## *People take on caring roles because of love and affection, a sense of responsibility, guilt, or cultural expectations and social norms*

physical and psychological problems (Schulz *et al* 1995, Lawrence *et al* 2008).

In most cases it is the spouse who takes on the carer role (Quinn *et al* 2010). If the individual with dementia is widowed or has no partner, it is often an adult child who takes responsibility. Evidence suggests there is a greater expectation on daughters to provide this care than sons (Ward-Griffin *et al* 2007). Other familial factors include geographical location, history or additional roles and responsibilities, such as having their own family. If there is no family then a close friend or neighbour may adopt the role of carer, but sometimes individuals face the illness on their own.

People take on caring roles because of love and affection, a sense of responsibility, guilt, or cultural expectations and social norms of filial responsibility. Caring for someone with dementia is almost always viewed in a negative light, although research by Svanberg *et al* (2011) with carers of individuals with early onset dementia found positive aspects including an increased feeling of gratification, altruism, personal wellbeing and a desire to reciprocate past support.

Walmsley and McCormack (2013) focused on the need to maintain high levels of communication between those with dementia and family members. Compromised communication poses a risk to both groups; individuals risk not being understood and making their needs known, often leading to frustration, anxiety and distress. Carers, by not understanding what is being said, risk inducing confrontation and may feel frustrated, helpless and hopeless. Walmsley and McCormack (2013) identified the need for meaningful reciprocal interaction because it improved the wellbeing of those with dementia and that of relatives. However, lack of understanding by carers and relatives about poor communication often contributes to carer burden or the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for older relatives (George and Gwyther 1986).

Informal carers are expected to manage an array of symptoms associated with dementia with no training and little support, such as wandering or impulsive behaviours, aggression, repeated questions and phrases, possible resistance to provision of care and also lack of recognition.

As a result the wellbeing of carers deteriorates and they can experience psychological difficulties such as caregiver stress in terms of sadness, loneliness and depression, and physical health problems. All of these have a negative effect on their ability to continue the caring role (Alzheimer's Association 2014).

There is evidence that informal carers experience a range of emotions such as guilt, anger, fear, helplessness, denial and depression (Markut and Crane 2005). Carer support groups, families, friends or counselling can help relieve the burden. Objective 7 of the National Dementia Strategy states that carers have a right to have their needs assessed (DH 2009a). However, a crisis in care may arise where caregiver burden exceeds resources. This crisis may be based on severity, accumulation or emergence of behaviour-related symptoms, caregiver exhaustion or caregiver illness (Vroomen *et al* 2013). If a crisis point is reached, older persons mental health services would recommend assessment at a specialist inpatient hospital. Avoiding institutionalisation is in the best interests of the person with dementia, but admission to hospital may be the only possible option to assess and treat any symptoms and determine a future care pathway (DH 2009a).

**Formal care providers** This is a person contractually employed in a health or social care setting, such as an acute psychiatric inpatient ward, care home or nursing home. Formal carers include support workers or registered nurses (RNs). They should receive dementia care training and have the appropriate skills, knowledge and continued education and support in the form of clinical supervision while working with patients or residents to ensure high standards of person-centred care. Nurses on acute psychiatric wards have high levels of occupational stress (Koivunen *et al* 2013).

Direct patient contact is one of the most satisfying aspects of mental health nursing (Wu *et al* 2010). However, the demands placed on RNs working on acute psychiatric wards – general shift management, paperwork, medication administration, ward rounds, care programme approach meetings, junior staff management and clinical supervision and liaison with other members of the multidisciplinary team such as social workers, occupational therapists or speech and language therapists – mean that this essential aspect of nursing care is diminished.

With reduced job satisfaction comes occupational burnout, causing work-related stress and sickness absence. In 2009, the Boorman review (DH 2009b) found that the direct cost of staff sickness absence was £1.7 billion a year, with NHS trust sickness absence rates ranging from 2% to more than 6%.

This in turn affects quality of care and safety of the ward environment because there is extra reliance on temporary and agency staff who might lack specialist training and skills.

In their review of nursing home staff attitudes towards residents with dementia, Brodaty *et al* (2003) identified that staff stress and burnout have a direct link to reduced resident wellbeing because there is less interaction between staff and residents. There are similarities between hospital and nursing home care as staff are still managing the symptoms that develop with the illness and the challenges that result for individuals and the staff treating and managing them.

In dementia care, continuity is important to ensure that patients feel safe and secure. If members of nursing staff are constantly changing it has a further negative effect on patient wellbeing.

The values and attitudes required by RNs to work with people with dementia are well documented (Norbergh *et al* 2006): compassion, sincerity, empathy, respect and empowerment. Nursing staff should work in partnership with those with dementia in an honest, open and therapeutic manner. These attitudes and values may be based on personal factors, knowledge, skills, training and experience of dementia care nursing, in addition to the organisational culture of the care environment.

Brooker (2007) discusses how care staff working with people with dementia should adopt the VIPS framework of person-centred care: values, individual approach, perspective of the service user and social environment. She stresses that person-centred care is only achievable if the larger organisation maintains an ethical code where those with dementia and nursing staff are valued.

If organisational culture is negative, this may influence nursing staff's attitudes. Norbergh *et al* (2006) state that this can 'result in their experiencing their own caring for the patient as meaningless and their work as worthless' and reduced job satisfaction. They imply that RNs' attitudes are of paramount importance when determining the quality of dementia care. Therefore, maintaining these core attitudes, values and ideals can improve standards of care and influence the guiding principles by which those with dementia are treated.

Nursing stress is encountered when these ideals are not achieved because of lack of resources or sufficiently skilled and educated staff to meet patients' complex behavioural, psychological and physical needs. However, there are numerous aspects that contribute to job satisfaction for nurses in acute psychiatric assessment wards that focus on dementia care (Zimmerman *et al* 2005). For example, when behavioural and psychological disturbances



are treated effectively and individuals are able to maintain a good quality of life.

When behavioural symptoms are treated, individuals with dementia will either be discharged home with community support, or if carer stress was high before admission, there has been a physical health decline or deterioration in cognitive status, successful discharge from hospital to a residential setting might be considered. High levels of job satisfaction among nursing staff in dementia care require on-going education, training, effective leadership and management of the clinical area with robust debriefing support mechanisms and clinical supervision to establish and maintain high quality care (Zimmerman *et al* 2005).

Conclusion

The complexities of dementia pose challenges for all. The profound influence of dementia on the lives of people experiencing the illness, their families and formal carers is well documented.

A collaborative partnership between all three groups is the most effective approach to improve care. Ensuring individuals have control over their illness is essential: education, treatment and care are vital to ensure that they are protected from malignant social psychology and disempowering processes. Education and training for carers focusing on positive interactions is needed. Formal carers require dementia knowledge and skills training to enable a person-centred culture to develop.

Training in understanding people’s impairments and how these affect their behaviour and personality will result in symptoms being managed skilfully, with empathy and an understanding of the messages being communicated. Identity changes throughout the pathway of the illness are significant, and evidence-based support methods are still being explored. An increased awareness and recognition of the trifactorial effect of dementia can help to meet individual needs and ensure high quality care and services.

Online archive

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Conflict of interest  
None declared

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